



## Components of a community model of dementia palliative care

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### Components of community model of dementia palliative care

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**Title:** Components of community model of dementia palliative care

**Abstract**

*Purpose:* The Model for Dementia Palliative Care Project will develop a service-delivery model for community-based dementia palliative care. Many countries provide dementia palliative care services, albeit with considerable variability within these. However, little is known about what service providers consider to be the most important components of a dementia palliative care model. This study aimed to address this knowledge gap.

*Design/methodology/approach:* An exploratory design using a survey method was used, as an initial phase of the wider project. A web-based survey was developed, piloted (n=5), revised, and distributed within five healthcare jurisdictions: the Republic of Ireland, Northern Ireland, England, Scotland, and Wales. The target population was health and social care professionals, policy-makers, and academics interested in dementia and palliative care. Content analysis of open-ended questions identified common themes; descriptive statistics were applied to the closed-ended questions.

*Findings:* Overall, N=112 complete surveys were received. Key care principles incorporated the philosophies of palliative care and dementia care; many described ‘holistic’ and ‘person-centred care’ as core. Important individual service components were support for carers, advanced care planning, information, education and training, activities for ‘meaningful living’, comprehensive disease management, coordinated case management, and linking with community health services and social activities. Barriers included poor availability and organisation of healthcare services, stigma, misconceptions around dementia prognosis, insufficient advanced care planning, and dementia-related challenges to care. Facilitators included education, carer support, and therapeutic relationships.

*Originality/value:* This study, as part of the larger project, will directly inform the development of a novel service delivery Model of Dementia Palliative Care for Ireland. The results can also inform service planning and design in other countries.

**Keywords:** dementia; palliative care; integrated care model

**Author classification:** Research paper

**Introduction**

Dementia is recognised internationally as one of the most significant healthcare challenges. Worldwide, around 50 million people have dementia, and there are nearly 10 million new

cases every year (World Health Organisation, 2019). Dementia is a degenerative, life-limiting illness. The average survival time from dementia diagnosis varies greatly depending on gender, dementia sub-type, age and severity of symptoms at diagnosis; however, one systematic review found that the average survival time is between 1.1-8.5 years (Brodaty ~~et al.~~, 2012). A more recent study of memory clinic patients, including those with young onset dementia, found a median survival time post-diagnosis of just 6 years (Rhodius-Meester ~~et al.~~, 2019). As there are no current curative treatments, all treatment is essentially palliative, and there is an imperative for research to improve the palliative care of people with dementia (PwD). PwD and their carers have been shown to have palliative care needs equal to those of cancer patients (Dempsey ~~et al.~~, 2015). However, the palliative care needs of PwD may be complicated by cognitive impairment, communication difficulties and responsive behaviours; presenting unique challenges to palliative care (Denning ~~et al.~~, Sampson and De Vries, 2019). Qualitative research has shown that while in many ways the basic palliative care needs of people are the same regardless of illness, families' experiences differ, for example families report extra stress when their dying loved one cannot be involved in decision making about their own end of life care (Fox ~~et al.~~, 2017). Although some national dementia strategies include a focus on palliative care, such as Ireland, England, Northern Ireland, ~~and~~ Sweden, ~~and~~ Scotland, many do not (Nakanishi ~~et al.~~, 2015).

The principles of palliative care and of dementia care are innately complementary. Person-centred care (Kitwood, 2011) is at the heart of good dementia care, and arguably (although not always explicitly stated) also palliative care. Both emphasise a holistic approach, recognising the importance of non-physical symptoms, and of quality rather than duration of life. Both emphasise the patient-family unit, and espouse the importance of multi-way communication and shared decision making, and of future care planning. A useful framework for optimal dementia palliative care has been agreed (Van der Steen, 2014), including, in addition to the above, continuity of care, recognition of dying, avoiding burdensome/futile treatments, and health and social care professional (HSCP) education. Worldwide, there remains a significant need to expand the research base for palliative and end-of-life care, in recognition of emerging global priorities, moving beyond cancer to examine diseases such as dementia (Denning, 2016). Within Europe, the Joint Programme-Neurodegenerative Disease (EU JPND, 2014) suggested the following priorities for palliative and end-of-life care research in neurodegenerative disease: needs assessment, the identification of transitions along the pathway, and *consideration of effective models across Europe*. However, few evidence-based models of dementia palliative care have been published.

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3 68 The Model for Dementia Palliative Care Project aims to explore existing models of palliative  
4 69 care for PwD in the community (theoretical models from the literature and actual clinical  
5 70 services), using a programme theory approach to describe key model components (context,  
6 71 focus, resources/input, service activities, outputs), and then translate these into a model  
7 72 relevant to the community. The principal aim is to develop a service delivery model  
8 73 incorporating key activities, and to provide a cost estimate and value to potential users of the  
9 74 model in Ireland. However, the model will be designed to be translatable to other healthcare  
10 75 systems and contexts. Multiple methods are being employed, including an initial exploratory  
11 76 survey to explore key healthcare stakeholders' views on what is a "good" model of palliative  
12 77 care for PwD living in the community.

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19 78 The guiding research questions of the exploratory survey were:  
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22 79 • What do stakeholders consider should be the key principles of care to inform a model  
23 80 for dementia palliative care?  
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25 81 • What do stakeholders consider to be the most important components or activities of  
26 82 such a model?  
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28 83 • How should such a model be organised?  
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30 84 • What are perceived barriers to such a model, and how might these be overcome?  
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36 86 **Methods**

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38 87 *Survey development*

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40 88 To identify what stakeholders consider '*a posteriori*' to be important in a model of dementia  
41 89 palliative care (based on their experience), a *de novo* survey was developed based on a  
42 90 literature review and the expert opinion of the project advisory group, consisting of  
43 91 academics and clinicians from dementia and palliative care.

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47 92 The majority of survey questions were open-ended, intended to elicit rich qualitative data.  
48 93 Two closed-ended questions asked respondents to rate the importance of a variety of  
49 94 'general aspects' and 'specific components' of a model for dementia palliative care (based  
50 95 on components identified in the literature, augmented by suggestions from the advisory  
51 96 group). These prompted respondents to rate aspects/components which they may or may  
52 97 not have considered in their responses to the earlier open-ended questions, using a 4-point  
53 98 Likert scale, with options 'not very important', 'somewhat important', 'very important', and  
54 99 'essential'.  
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A paper version was piloted among a convenience sample (n=5). Following feedback, a modified electronic version was created using LimeSurvey®, and further piloted for usability (n=3). The survey questions are provided in Table 1.

<<< **INSERT TABLE 1 ABOUT HERE** >>>

### *Sampling*

Surveys were distributed electronically in the Republic of Ireland, Northern Ireland, Scotland, and England and Wales (five countries, with the latter two sharing a healthcare system). The rationale for choosing these was their comparable healthcare systems, and good contextual similarity to Ireland. A purposive and “snowball” sampling methodology was used (Palinkas *et al.*, 2015). Inclusion criteria were HSCPs/managers/policy-makers or academics with expertise in dementia palliative care. The initial purposive recipient pool was informed by national healthcare databases and websites, the knowledge of the research team and their extended networks, in each region, and by direct contact with service leads for dementia and for palliative care in each country. Priority was given to targeting key stakeholders and experts, over final sample size. Initial recipients were asked to forward the email to any contacts they considered relevant, to increase inclusion.

### *Data analysis*

Raw data were imported into Excel and cleaned. Descriptive statistics and graphs illustrated the quantitative data. The open-ended questions provided abundant qualitative data, which was analysed using Thematic Content Analysis (following Braun and Clarke’s 2006<sup>9</sup> framework). The first stage looked for key themes within individual survey questions, using an inductive and descriptive approach; subsequent stages of analysis considered themes across the full dataset deductively, driven by the guiding research questions. Three researchers were involved in coding and analysis, and sections of data which were doubly coded were compared to increase rigour of analysis and interpretation. Finally, to make the data more “useful” for our programme theory informed approach we mapped out the key inputs, activities, outcomes as a modified logic model. This is a graphic depiction of the shared relationships between the resources, activities, outputs, and outcomes/impacts for a healthcare program (Centres for Disease Control and Prevention, 2018).

### *Ethics*

This study received ethical approval from the Cork Research Ethics Committee (reference: ECM4(h)/ECM3(zzzzz)). The survey landing page provided detailed study information and outlined that by completing and submitting the survey, participants were consenting to take part.

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134     *Funding*

135     This research was funded by the Health Research Board, who had no role in the research

136     design or conduct.

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138     **Results**

139     **Survey respondents**

140     After deleting cases with significant missing data, the final sample was 112. It wasn't

141     possible to calculate response rate, as some organisations didn't provide the number of

142     subscribers on their mailing lists, and owing to the "snowball" approach. Responding sample

143     details are in Table 2.

144     <<< INSERT TABLE 2 ABOUT HERE >>>

145

146     **Ranking the features and activities of a model**

147     Survey participants ranked the importance of general aspects and specific activities of a

148     community dementia palliative care model. Results are shown in figures 1 and 2.

149     <<< INSERT FIG 1 AND FIG 2 ABOUT HERE >>>

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151     **Qualitative analysis of open-ended question responses**

152     Most of the data produced by the survey method was rich qualitative data. The four guiding

153     research questions were used to organise the final themes in the data, thus the results are

154     presented as addressing each research question below.

155     **I. What do stakeholders consider to be the key principles of care that should inform a**

156     **model?**

157     Responses merged the philosophies of palliative care and good dementia care, and included

158     domains of the framework for dementia palliative care (Van der Steen, 2014). Respondents

159     emphasised a "holistic" or "palliative care" approach, including the four pillars of palliative

160     care i.e. physical, psychological, social and spiritual care. Equally, many emphasised

161     person-centred care as a core philosophy, i.e. *"all care should be person-centred and*

162     *relevant to the individual's needs"*. The latter may be summarised as combining

163     individualised care with the aim of optimising quality-of-life.



Some respondents addressed the core philosophies more generally, highlighting the care principles of “empathy” including respect, dignity and compassion. Respecting PwDs’ wishes to stay at home was mentioned, as was respecting the families’ wishes. Others included end-of-life care specifically:

*“A model focussed on wellbeing and quality-of-life that is open and honest about what to expect during the end-of-life process for people with dementia” (Occupational Therapist, acute hospital)*

## **II. What do stakeholders consider to be the most important components/activities of a model?**

*Interventions to support “meaningful living”.* This theme concerned having access to specific interventions targeting the four pillars of palliative care. These activities should be meaningful to the PwD and help to maintain wellbeing. Examples included cognitive stimulation/rehabilitation therapies, reminiscence therapy, social activities, music/art therapies, gardening, and respite facilities in local areas. Wherever possible these should be offered as home-based interventions, with follow-up.

*“Access to regular therapies brought to the person in the community. Not for them to travel to the service!” (Clinical Nurse Manager, social care)*

Others mentioned social activities e.g. *“support for PwD to attend a match, go to the pub, mass or visit a friend”*. The importance of *“regular re-assessment of needs”* was highlighted so the PwD is referred to the appropriate treatments, therapies and supports.

*Support for the carer* was a component considered essential for this community model. Having formal and peer-support networks for carers and families was highlighted to provide emotional and social and practical support. Sitting services, effective respite, 24/7 support, and fast access to services were all critical to *“ease carer burden”* and support them to care for their loved one at home for as long as possible. Of these factors- increasing home help availability- was considered most critical:

*“Appropriately trained home care and funding for it” (Medical Social Worker, acute care)*

*“Lack of home care packages- huge barrier to delivering community palliative care” (Consultant in Geriatric Medicine, acute hospital and hospice)*



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3 195 Importantly, the family should be part of the care team and involved in care decisions. Some  
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5 196 respondents felt that this could be improved in the context of palliative care, for example  
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7 197 HCPs *“do not always listen to family members when they are trying to tell them about pain”*  
8 198 (Admiral Nurse, community palliative care).  
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12 200 *Information, education, and training* was a key theme. It’s important that PwD and families  
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14 201 are offered education, at an appropriate pace, about the nature of the disease, and what  
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16 202 palliative care supports are available should they need them.

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18 203 Suitably trained and motivated staff are needed. Dementia professionals should all be able  
19  
20 204 to provide generalist palliative care support. Equally, palliative care staff should have training  
21  
22 205 in dementia care, and/or a dementia specialist should be available to palliative care teams or  
23 206 situated in hospices. As one Dementia Specialist Nurse in a hospice setting wrote:

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25 207 *“I think there is lack of understanding on what advanced dementia is and how it presents.”*

26 208 *(Mental Health Nurse Specialist in Dementia, Hospice)*  
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29 209 Other related activities were access to education courses, specifically around advanced  
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31 210 dementia and end-of-life care in dementia for both families and professionals, and moving  
32 211 and handling training for carers.

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34 212 Information resource packs were suggested so that the PwD or carer can self-refer to  
35  
36 213 services. One respondent suggested having a manned information stand at clinics *“for*  
37 214 *handing out information and whatever the client or family member may need at that time”*  
38 215 (Care Home Liaison Nurse, community).  
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43 217 *Supportive and safe environments* which are comfortable and familiar to the PwD was also  
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45 218 mentioned, often referring to supporting PwD to live in their homes as long as possible.  
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47 219 Having *“access to suitable equipment as needed”* to allow care at home was considered  
48 220 important, along with *“providing equipment as a matter of urgency”*. Adopting *“preventative*  
49 221 *approaches”* e.g. falls prevention was related.

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51 222 Creating wider dementia friendly environments in the community through advocacy,  
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53 223 education and *“more local community awareness raising”* was highlighted. Enabling  
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55 224 environments where hospital, community & primary care providers are supported to provide  
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57 225 palliative care were discussed. Supportive environments are important throughout all stages  
58 226 including a *“therapeutic environment at preferred place of death”*.  
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228 *Symptom management* was another common theme; aspects discussed were, management  
 229 of pain; bowel and bladder; skin care; behaviour; medication; nutrition; swallowing; and  
 230 prevention and management of delirium; falls. Where possible these should be managed at  
 231 home, by the carer, supported by community care teams. In advanced disease more  
 232 expertise from the MDT might be needed, e.g. the palliative management of pain (especially  
 233 for people who cannot verbally express pain), medication, and controlling symptoms. Access  
 234 to the MDT within primary care was suggested.

235

236 *Advanced care planning (ACP)* was a key activity. ACP should be undertaken early, and  
 237 reviewed regularly. Several respondents expressed that PwD and their family should be  
 238 encouraged to engage in ACP following diagnosis; to use this opportunity of contact to  
 239 discuss the importance of having conversations about the end-of-life stage early in the  
 240 disease prognosis:

241 “A plan from diagnosis, where the post-diagnostic team gently start to discuss ACP with the  
 242 person and family- this can be updated/changed as needed whilst the person still has  
 243 capacity. This will then influence the care given in the palliative stages!” (Palliative Care  
 244 Nurse Specialist, hospice and community)

245

246 *Excellent end-of-life care.* To ensure a ‘good’ death, PwD should be supported to die at their  
 247 preferred place (e.g. home or hospice), and effective symptom and pain management with  
 248 an appropriate tool to recognise pain must be provided. Trained HCPs are key “to ensure a  
 249 respectful and dignified passing”. Bereavement support and end-of-life counselling are  
 250 crucial to support the carer.

251

### 252 **III. How should a model be organised?**

253 *Comprehensive support.* Current services were criticised as “very limited and sporadic”.  
 254 Respondents felt that a broad range of services should be available, so that a  
 255 comprehensive care plan can be tailored to individual situations, including financial,  
 256 emotional, physical, social, spiritual and bereavement support, and practical advice.

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257 There should be regular comprehensive needs assessment throughout the PwD’s journey.  
258 This included receiving regular and standardised palliative care needs assessments, and  
259 specialist palliative care (SPC) for patients with complex needs.

260 It’s important that services are flexible and responsive to ensure timely identification of, and  
261 appropriate responses to, potential crises:

262 *“the model should be flexible so that it can be truly patient-centred” (Admiral Nurse Lead,*  
263 *community)*

264 No one model will be able to support the various needs of individuals at different times of  
265 their dementia journey, so a flexible model is key:

266 *“Each individual will need support and advice at different points in their journey.” (Admiral*  
267 *Nurse Lead, community)*

269 *Integration of services.* This involves integrating primary care, community palliative care,  
270 mental health, voluntary organisations, etc., with good links to acute services. Excellent  
271 communication between these settings is a necessity. Many felt that dementia and palliative  
272 care services must be integrated, i.e. that generalist and specialists should work together, for  
273 example that a Geriatrician remain primarily involved in care throughout, with support from  
274 SPC as required.

275 Many highlighted the importance of a key worker to *“develop a relationship with family and*  
276 *PwD to coordinate support”* that is truly comprehensive, i.e. linked in with all relevant  
277 services.

278 *“Having a key worker (such as Admiral Nurse) involved start to finish to coordinate care and*  
279 *ensure a palliative care approach is achieved from point of diagnosis through to after death*  
280 *support for families” (Admiral Nurse, hospice)*

282 *System level.* At the highest level, key elements included that the model is linked to other  
283 relevant pathways, is provided as part of ‘mainstream’ services, that adequate facilities  
284 within services are available, that electronic patient data is available to facilitate  
285 communication, and that there is a *“feedback loop”* from service users to enhance the  
286 component services.

287

Access. Many felt that PwD should have equal access to SPC as people with cancer or any other life-limiting condition.

*“People need to be identified as having a chronic disease and to be on the palliative care register so regular monitoring of their care is given” (Admiral Nurse, charity)*

Ease of access to all services was also stressed, whether palliative-, dementia-, or care-of-the-older-person specific, to help PwD to remain at home. Services should be available nationally so a PwD is not limited by their locality, and services should be available free at point of access.

*Palliative care consideration from diagnosis.* A greater emphasis on addressing the needs of PwD from diagnosis to end-of-life is needed. Not everyone diagnosed with dementia is placed on the palliative care register (where available), which highlights the lack of recognition that dementia is a terminal illness. A *“recognition by all that a palliative approach to dementia care is best”* is crucial for successful organisation. The need for a clearly defined pathway for dementia aligned to an end-of-life care framework was also expressed:

*“There needs to be a clearly defined pathway for dementia aligned to the End-of-Life Care Operational System phases as to who will be involved and lead and how and where handovers should take place on a planned basis” (Assistant Director, primary/community and secondary care)*

#### **IV. Who should be involved?**

*Multidisciplinary approach.* Many professions and disciplines were mentioned as important for a community model of palliative care for dementia, including GPs, community teams, consultant geriatricians, psychogeriatricians, old age psychiatrists, dementia and palliative care nurse specialists, community/public health, psychiatric nurses, psychologists, social workers, therapists, and spiritualists. Furthermore, physiotherapists, dieticians, pharmacists, voluntary groups (e.g. Alzheimer UK or Alzheimer Society of Ireland), volunteers, and local ‘grass roots’ leaders were also mentioned. Finally, the PwD and carer were included in the MDT by numerous respondents. It is important that the MDT works together and coordinates all inputs to *“place as little burden [as possible] on carers and family”*, while including them in care and care planning. Involving district nursing teams in palliative care approaches is also crucial. Recognising the role of every HCP is important, for example the role that SLTs and

OTs can play in managing communication difficulties and adapting homes quickly and safely was expressed:

*“SLTs have a huge and largely unrecognised role in managing cognitive communication difficulties and dysphagia, which is an invariable consequence of dementia”. (Speech and Language Therapist, private practice)*

## **V. What are perceived barriers to a model?**

### ***Poor Organisation of Healthcare Systems***

*Lack of resources.* Respondents discussed many problems at the wider healthcare service level. A lack of funding and resources was mentioned frequently. One respondent felt that there is an *“over reliance on voluntary agencies to plug holes in the health system”*.

Dementia palliative care was seen as being costly to provide considering the required home care, 24-hour care, including care for the carer, and rapidly rising numbers of PwD. There’s a lack of community palliative care (for any illness), and inadequate home supports including overnight support and on-call GPs. Person-centred care interactions require time, when HCPs are already stretched; currently community care is too focused on completing tasks. There is also a perceived shortage of disciplines such as consultants and nurse specialists, and specialists in dementia with palliative care training, and vice versa. Where good pockets of services existed, this was inequitable and varied by location.

*Poor quality of services.* Other services may be available, but not fit for purpose, typically existing community services. *“No alternative to long-term care”* was frequently mentioned as a barrier. Options for respite were poor, as were dementia-friendly leisure activities.

*Poor organisation and delivery.* Barriers were also identified in how the system is organised. There is an *“over-reliance on the medical model”*, on providing physical care. This is compounded by the poor integration between health and social care:

*“Professionals are working in silos with poor communication between disciplines”.  
(Programme Manager, health agency)*

Services are difficult to navigate in the context of a complex decision framework. Many PwD aren’t assessed for needs until there is a crisis. Hence, there is a need for *“a good referral pathway or link to specialist services without having to go through A&E”*. Another problem

was that as nursing homes are viewed as already providing end-of-life palliative care, they are deprioritised for SPC input.

*Attitude.* Some felt that there is a general lack of interest in society, and among some HCPs, in advancing dementia care as a priority, the following quotes are illustrative:

*“[there are] few consultants with a specialist interest in this area.” (Consultant in Geriatric Medicine, acute hospital and hospice)*

*“Specialist palliative care staff feel that this is not where their skills and practice should be directed” (Nurse Consultant End of Life, community)*

### **Misconceptions of Dementia Palliative Care**

*Misconceptions about dementia* were frequently cited as barriers. Dementia is not being recognised as life-limiting, preventing HCPs from appreciating the benefit of palliative care involvement. It was also felt that there is a general stigma in society (including among HCPs) about dementia, that PwD may be “*written off*”. Related was a fear of non-cognitive symptoms of dementia (i.e. responsive behaviours) stemming from a lack of education. Many HCPs who aren’t dementia specialists may not feel confident in caring for people with non-cognitive symptoms manifesting through behaviour.

*Misconceptions about palliative care* were also pervasive. Not surprisingly, palliative care is “*focused mainly on cancer patients*”, although some, particularly in England, reported that their local SPC service would see PwD. Equating palliative care with end-of-life care or SPC, was common.

*“Some healthcare professionals believe that palliative care can only be provided by SPC services” (Clinical Nurse Specialist, community palliative care)*

These misconceptions led to access barriers; some hospices won’t accept PwD, and other hospices felt unable to manage the longer term needs of PwD.

### **Delivery of Dementia Palliative Care**

*Advance Care Planning.* A lack of ACP was a significant and common barrier identified. Too late referrals to SPC impeded excellent end-of-life care, and reactionary interventions



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383     impeded good care throughout the illness. Respondents felt that there is also a “*lack of*  
384     *robust training for health professionals*” to deal with all stages of dementia and not just  
385     diagnosis.

386     *“Much of geriatric training has been in diagnosis and management with little focus on ACP*  
387     *and end-of-life.” (Consultant in Geriatric Medicine, acute hospital and hospice)*

388     One respondent recounted her experience of the reluctances of HCPs to engage in early  
389     ACP:

390     *“The main gap in our area is with the post-diagnostic team being reluctant to become*  
391     *involved in ACP discussions” (Palliative Care Nurse Specialist, hospice and community)*

393     There appears to be no clear guidance on when and by whom this discussion should take  
394     place among HCPs particularly when dealing with early stage dementia.

396     *Dementia specific barriers.* Dementia that isn't diagnosed, or delayed diagnosis, impedes  
397     effective palliative care. Difficulties in prognostication or staging dementia were  
398     acknowledged. Physical needs assessments, including pain, are more difficult in PwD and  
399     require specific skills. Some felt that it takes more time to care for PwD, and that they need a  
400     higher level of home support.

402     **VI. What would facilitate implementation of a model?**

403     *Funding.* Sufficient funding is essential for adequate resources and increase staffing levels,  
404     particularly within the community. With adequate funding, the core components of the model  
405     can be supported.

407     *Education and training.* This included training in dementia and in palliative care for all HCPs  
408     who are interacting with PwD. Specific topics may include communication, including non-  
409     verbal communication, specific training in ACP and end-of-life for both healthcare  
410     professionals and carers, reminiscence for PwD and carers, education with carers in the  
411     home “*on what to expect with palliative illness and dementia*”, and broader education on  
412     living with dementia:



“Education on what the world is like for someone living/dying with dementia - for healthcare professionals, family, carers and community groups so that individuals in the wider community know how to support someone with dementia” (Dementia Champion, hospice)

**Carer support.** Any model requires significant unpaid or informal caring from a family member, who may often be older, frail, and/or ill themselves. Respondents mentioned group community supports, courses in caring, and better respite options.

“Respite is critical to keeping people in their own homes especially as the illness progresses.” (Consultant Nurse in Palliative Care, acute hospital)

**Therapeutic relationships.** Respondents felt it essential that staff are friendly, know the PwD and family well, and practice clear, effective communication. This would facilitate person-centred care. The model should strengthen relationships between PwD and their carers as a supportive family is often the key element which enables PwD to remain in the community.

**Other facilitators.** A range of practical elements were mentioned as facilitators, these included: transport to community services, assistive technologies, home equipment, reliable assessment and prognostication tools.

## Logic Model

A logic model (figure 3) was developed to illustrate how the emergent themes might be translated to a healthcare model. Key themes were mapped onto the elements of ‘input’, ‘intervention’, ‘components’, ‘intermediate and long-term outcomes’, and ‘contextual and external factors’.

<<< **FIGURE 3 ABOUT HERE** >>>

## Discussion

A model of care broadly describes a framework that brings together regulatory, organisational, financial, and clinical aspects of service provision to outline best practice in patient care delivery (NCPPC, 2019). While current practices around dementia palliative care are suboptimal, having clear models will assist healthcare providers in different

1  
2  
3 444 countries provide better care and to a higher standard. Although increasingly dementia is  
4  
5 445 being recognised as a terminal illness and palliative care is being increasingly promoted, a  
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7 446 challenge remains in defining what works, and/or would work well in real-life practice. This  
8  
9 447 survey addressed this challenge. Responses were collected from stakeholders across five  
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11 448 different countries with four healthcare systems and a relative degree of consistency was  
12  
13 449 observed, with key themes emerging. While the initial model will be developed for an Irish  
14  
15 450 context, the current results have wider relevance.

16  
17 451 The seminal EAPC white paper (Van der Steen, 2014) identifies 11 domains of optimal  
18  
19 452 dementia palliative care, namely: person-centred care, communication and shared decision-  
20  
21 453 making; optimal treatment of symptoms and providing comfort; setting care goals and  
22  
23 454 advance planning; continuity of care; psychosocial and spiritual support; family care and  
24  
25 455 involvement; education of the health care team; societal and ethical issues. prognostication  
26  
27 456 and timely recognition of dying; avoiding overly aggressive, burdensome or futile treatment;  
28  
29 457 and applicability of palliative care. All of these domains emerged as themes within our  
30  
31 458 survey, reinforcing their relevance. However, our “bottom-up” qualitative approach  
32  
33 459 highlighted some interesting nuances within these themes. Furthermore, by framing the  
34  
35 460 results in a logic model we highlight what a service-delivery model of dementia palliative  
36  
37 461 care might look like, and the interplay between different model domains or components.

38  
39 462 There was a significant degree of consistency in the responses provided by key  
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41 463 stakeholders, even across the different regions; these are represented in the modified logic  
42  
43 464 model. The inputs required for the model include funding and resources, and staff education  
44  
45 465 and time, however longer-term outcomes may provide a cost saving to the health service,  
46  
47 466 e.g. less unnecessary hospital admissions (O'Shea and Monaghan, 2017).

48  
49 467 As highlighted in the logic model, contextual and external factors must be considered when  
50  
51 468 planning the implementation of this model, such as the ageing population and current  
52  
53 469 attitudes towards dementia by the public, politicians, and HCPs. Raising awareness about  
54  
55 470 palliative care and dementia among the general public is important to normalise this  
56  
57 471 connection. Creating awareness and educating about dementia generally will help to  
58  
59 472 develop supportive communities and environments for PwD and their carers, which is  
60  
473 important for PwD to remain living at home for longer (Lin, 2017).

474  
475 Potential core components of the model were identified as person-centred care,  
476  
477 comprehensive care, integrated care, accessible care, timely care, and care for carer.  
478  
However, the different model components are inextricably linked, for example: having rapid  
access to services supports care at home; earlier access to services promotes earlier ACP  
and better end-of-life outcomes. The broad components can be aligned with existing

frameworks such as the Irish National Clinical Programme for Palliative Care's 'eight foundations' (NCPPC, 2019), and the 'six ambitions' of the UK's Ambitions for Palliative and End of Life Care framework (2015); both of which were developed as relevant for the palliative care of all adults with a life-threatening illness. However, many issues specific to dementia have been highlighted, hence a specific integrated model for dementia palliative care is crucial (Van der Steen, 2014; Tolson *et al.*, 2017). Our study indicated the perceived importance of components that would perhaps not be part of usual palliative care services, to support *meaningful living*, such as cognitive stimulation/rehabilitation therapies, reminiscence therapy, etc. The need for *supportive and safe environments* is also quite dementia specific. The particular challenges of non-cognitive symptoms manifesting through behaviour were also highlighted, along with difficulties in prognostication.

Reflecting the above unique needs of a PwD, it is not surprising that providing information, education, and training is integral to the implementation of this model. Others have noted that a skill and discipline mix, alongside an investment in staff development, is required for effective dementia palliative care (Tolson *et al.*, 2017). Even if a SPC service does not provide a dementia palliative care service, as people live longer and dementia in the older population becomes more frequent, more people in the service will have co-morbid dementia. Therefore, it is imperative that SPC professionals upskill in dementia care. Equally, dementia care professionals need to recognise that a palliative care approach can be (and often already is) provided by all disciplines caring for older people and/or those with dementia, and to upskill where appropriate. Critically, these two services must work together within an integrated care model. Further recognition of the value of different non-medical disciplines will also support comprehensive care.

Person-centred care is recognised as a core value for dementia care (Kitwood, 2011). This dovetails nicely with the holistic approach of palliative care. To facilitate this, HCPs must communicate effectively with each other whilst including the PwD and their family through regular follow-ups. ACP is a key activity, associated with better end-of-life outcomes for PwD and their carers (Dixon *et al.*, Karagiannidou and Knapp, 2018). All HSCPs can play a role in facilitating ACP (Scott *et al.*, 2013).

Having a 'key worker' is an important component of the model which can help to keep the lines of communication open between the PwD, their families, and the care team. A support worker role has been shown to improve the quality-of-life of the PwD and the carer, reduce carer burden, improve symptom severity and reduce institutionalisation rates (Goeman *et al.*, Renehan and Koch, 2016). The role is facilitated by ensuring that the key worker/support worker has a skilled background, providing ongoing follow-up (home visits, via phone) that is

514 based on needs and that they have the time and ability to develop relationships  
 515 (Goeman [et al.](#), ~~Renehan and Koch~~, 2016).

516 Most PwD live in the community (Pierse [et al.](#), ~~O'Shea and Carney~~, 2019). Support for family  
 517 members and carers to provide care is essential to a community-based model. Effective  
 518 respite options (O'Shea [et al.](#), 2017), and community and out-of-hours support services are  
 519 needed to support the PwD to remain at home (Kim [et al.](#), 2012). This support needs to be  
 520 available and offered to carers regularly regardless of their health status, as any carer is  
 521 prone to experience burnout which may result in the carer feeling that they can no longer  
 522 care for the PwD at home (Donnelly [et al.](#), 2015).

523 Another key strength of the current draft model is that it considers what aspects of palliative  
 524 care may be delivered to PwD at any disease stage; many frameworks focus on palliative  
 525 care for advanced dementia only (Tolson [et al.](#), 2016). Aspects like approaching ACP early  
 526 in the disease and having a skilled dementia key worker who can link into palliative care  
 527 supports early if needed, extend the remit of palliative care to a whole disease focus.

528 For any such model to be successful, its implementation must be carefully considered  
 529 (Moore ~~et al.~~ [et al.](#), 2015). Tolson ~~et al.~~ [et al.](#) (2016) discuss the Prudent Healthcare  
 530 Paradigm- the delicate balancing act between effective and efficient policy making and policy  
 531 implementation in relation to advanced dementia. This paradigm acknowledges the  
 532 economic pressures and inequalities in provision which mean that existing care systems  
 533 cannot simply expand to meet the challenge of their ageing populations. Instead  
 534 transformational change is required in which everyone takes responsibility for health and  
 535 wellbeing in a united and integrated way. In many countries the context for such a change is  
 536 positive. In Ireland, and other European countries, there is a rapidly growing recognition by  
 537 governments, healthcare systems, and policy groups of the importance of palliative care for  
 538 non-cancer illnesses including dementia. Ireland has a National Dementia Office with a  
 539 specific remit to implement the National Dementia Strategy, and of note the strategy,  
 540 perhaps reflecting its relatively later development (in 2014) than strategies in other European  
 541 countries, has a very strong focus on palliative care. However close working with the Irish  
 542 National Clinical Programme for Palliative Care would be critical to successful  
 543 implementation.

544 Some limitations of the current study should be noted. The survey was modest in size with  
 545 n=112 respondents across five countries. Positively, distribution was targeted so that  
 546 respondents represented key informed stakeholders, however no claims to  
 547 representativeness can be made. Furthermore, the components represented in the logic  
 548 model are tentative, and the final model will need to be informed by further research,

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2  
3 549 including site visits and evaluations and further in-depth stakeholder consultation to include  
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5 550 PwD. These components however shed light onto what the potential model might look like,  
6  
7 551 and are a useful starting point to inform further research.

## 8 552 **Conclusion**

10  
11 553 Utilising a palliative care approach can improve the outcomes for PwD and their carers,  
12  
13 554 especially when a PwD's illness progresses to advanced dementia. Such outcomes may  
14  
15 555 include improved quality-of-life for both the PwD and their family, improved quality-of-care,  
16  
17 556 better clinical outcomes, more PwD dying in their preferred place, improved patient  
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19 557 experiences, cost saving to the health service, and PwD being treated with respect, dignity  
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21 558 and compassion. While the relevance of a palliative care approach for PwD is now widely  
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23 559 accepted, the challenge has remained in how to achieve this in practice. The results of this  
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25 560 study address this by informing a wider research project to develop a service-delivery model,  
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27 561 initially for Ireland, but with potential for adaptation by other national health services, or other  
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29 562 key groups who provide dementia and or palliative care services..  
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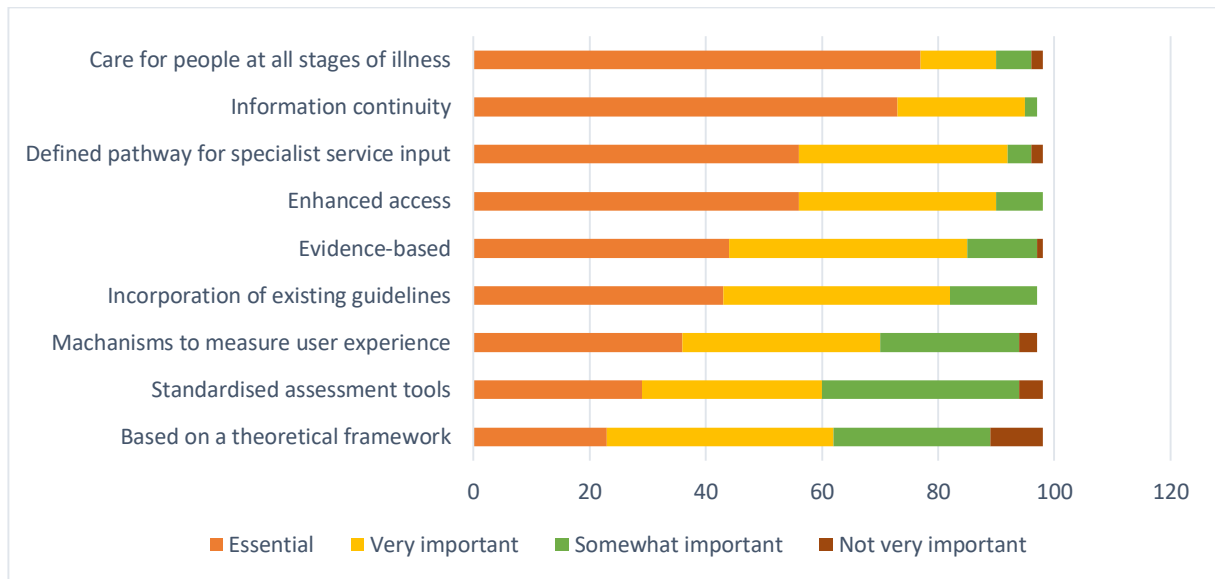
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**Table 1. Survey question items**

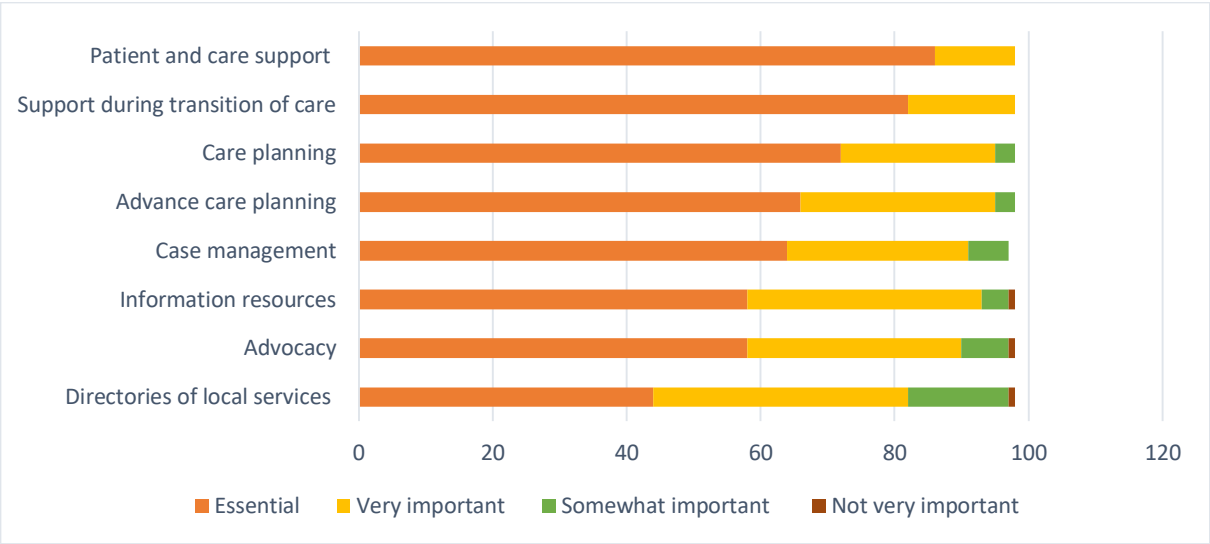
Open-ended items	
Question 1	What do you think a good model of palliative care for people with dementia in the community looks like?
Question 2	What principles of care should inform such a model?
Question 3	In your opinion who are the key people/professionals who should be involved in a model for palliative care for people with dementia in the community?
Question 4	In your opinion, what are the key activities (e.g. component, intervention, other) that should be included in a model for palliative care for people with dementia in the community?
Question 5	Do you have any other comments relating to the above questions?
Question 6	Please list any current barriers that you can think of to providing palliative care to people with dementia living in the community.
Question 7	Please comment on any ways in which these barriers might be overcome.
Question 8	We would like to hear about examples of good practice. Please provide any example, from your experience, of what has worked well in the past for providing palliative care to people with dementia. This can be a model, component, a way of working, or other.
Closed-ended items	
Question 9	Below we have listed some general aspects of a good model of palliative care for people with dementia. Please tell us how important you think each aspect is, by choosing from <i>Not very important, Somewhat important, Very important, or Essential</i> . Enhanced access Standardised assessment tools Information continuity Incorporation of existing guidelines on pharmacological and non-pharmacological Treatments Defined pathways for specialist service input Mechanisms to measure user experience Care for people at all stages of illness (i.e. early to advanced dementia) Based on a theoretical framework Evidence-based Other (please specify)
Question 10	Below we have listed some specific components of a good service for palliative care for people with dementia. Please tell us how important you think each component is, by choosing from <i>Not very important, Somewhat important, Very important, or Essential</i> . Care planning Case management Advance care planning Advocacy Patient and carer support Support during transitions of care Information resources Directories of local services Other (please specify)

**Table 2.** Respondents' Demographic Data (N=112)

(Primary) discipline	N	Country/Region	N	Gender	N
Nursing	50	England	43	Female	79
Community & Social Care	15	Republic of Ireland	25	Male	13
Doctor	11	Northern Ireland	22	Missing	20
Academia	8	Wales	5		
Physio, OT, SLT, Psychologist	8	Scotland	2		
Other	7	Missing	15		
Missing	13				



**Fig 1:** Ranking of general aspects of a good model of palliative care for people with dementia.



**Fig 2:** Ranking of specific components of a good model of palliative care for people with dementia.

